

# Community Outreach at Biomedical Research Facilities

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For biomedical researchers to fulfill their responsibility for protecting the environment, they must do more than meet the scientific challenge of reducing the number and volume of hazardous materials used in their laboratories and the engineering challenge of reducing pollution and shifting to cleaner energy sources. They must also meet the public relations challenge of informing and involving their neighbors in these efforts. The experience of the Office of Community Liaison of the National Institutes of Health (NIH) in meeting the latter challenge offers a model and several valuable lessons for other biomedical research facilities to follow. This paper is based on presentations by an expert panel during the Leadership Conference on Biomedical Research and the Environment held 1–2 November 1999 at NIH, Bethesda, Maryland. The risks perceived by community members are often quite different from those identified by officials at the biomedical research facility. The best antidote for misconceptions is more and better information. If community organizations are to be informed participants in the decision-making process, they need a simple but robust mechanism for identifying and evaluating the environmental hazards in their community. Local government can and should be an active and fully informed partner in planning and emergency preparedness. In some cases this can reduce the regulatory burden on the biomedical research facility. In other cases it might simplify and expedite the permitting process or help the facility disseminate reliable information to the community. When a particular risk, real or perceived, is of special concern to the community, community members should be involved in the design, implementation, and evaluation of targeted risk assessment activities. Only by doing so will the community have confidence in the results of those activities. NIH has involved community members in joint efforts to deal with topics as varied as recycling and soil testing. These ad hoc efforts are more likely to succeed if community members and groups have also been included in larger and longer term advisory committees. These committees institutionalize the outreach process. This can provide the facility with vocal and influential allies who create an independent line of communication with the larger community. **Key words:** active and informed public outreach, community involvement, defusing public outrage, public/private partnerships. — *Environ Health Perspect* 108(suppl 6):1009–1013 (2000). <http://ehpnet1.niehs.nih.gov/docs/2000/suppl-6/1009-1013goldman/abstract.html>

The panelists have chosen to address principles of community outreach from the perspective of replication or modeling. No two agencies face exactly the same issues, but common to all community confrontations with biomedically based organizations are perceptions of risk, secrecy, and hidden agendas. Presented here are approaches to handling fear and uncertainty, models for developing community outreach programs, and suggestions for maintaining positive relationships with the community. The term community includes neighbors to a biomedical research facility, county government, and state agencies.

## Community Risk Perception

When communities are faced with the possibility of unknown and complex hazards, they commonly and quite understandably react with suspicion and even a collective sense of fear. This happens whether the hazards involve waste sites, landfills, chemical plants, or biomedical research facilities in the community. This collective fear can be fed by misinformation or insufficient information about the nature and extent of potential risks to public health and the environment,

as well as a sense that the community is helpless to influence the decision-making process associated with controlling and remediating these risks.

A common issue for potentially affected communities is how to measure the risks associated with a site, and how to determine if they are absolute, relative, or exist only in the perception of the at-risk population. The U.S. Environmental Protection Agency uses a formal hazard ranking system (HRS) to compare sites and prioritize them for cleanup, but HRS is a complex model that focuses on Superfund enforcement issues. It is insensitive to non-technical issues and does not allow for community input. For these reasons, the HRS model is not a useful tool for public involvement or community-based decision making.

If community members are to be informed participants in the decision-making process for siting a medical research facility or for dealing with any other potential source of risk in the community, they must have a simple yet robust model available for evaluating and comparing all of the environmental hazards in their community. To be useful in community-based decision

making with respect to risk management and remediation, this model should have the following characteristics:

a) It should be usable and valid when applied at the community level and capable of assessing and comparing site-specific sources of potential harm to human health and the environment.

b) It should be sensitive to public perceptions with regard to risk but also provide a way to educate community members about potential sources of risk.

c) It should be easy to use, without complex submodels, extensive computer modeling, or extensive mathematical manipulations.

d) It should maximize the use of existing data resources such as web-based information on population, weather, and the fate and toxicity of environmental contaminants.

e) It should produce results readily explainable to the public, especially the stakeholders most at risk, in a manner that permits the evaluation of alternatives upon which community decisions can be made.

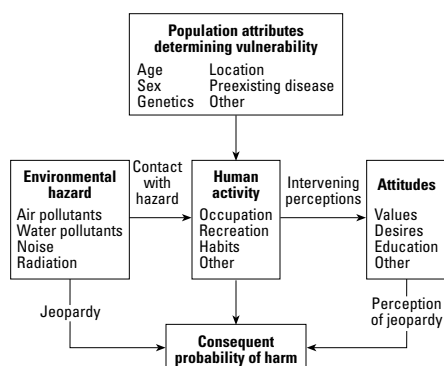
Components of such a community-based model should include those generally considered in any risk assessment: some measure of the actual or potential harm associated with the hazard, and some measure of the probability and/or extent of exposure to that harm. However, an additional factor needs to be incorporated to account for societal or community perceptions associated with the hazard and exposure to it. Figure 1 illustrates a paradigm introduced in 1981 to include these perceptions in the risk assessment process (1). Since that time, of course, there has been an increasing public awareness of environmental risks and a considerable change in the public's attitudes about the community's role in deciding which hazards, and what levels of risk, are acceptable.

At least three levels of input are needed for comparative risks to be assessed in a manner

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**Figure 1.** Interactions among functional societal variables and environmental jeopardy.

appropriate for community-based decision making:

First, information and data are needed for identification and characterization of the individual sources or loci of risk in the community, such as industrial discharges, existing depositories and regulated sites, and the specific nature of the constituents manufactured, stored, or processed in the community, as well as any available information on the toxicity, fate, and behavior of specific constituents.

Second, information and data are needed for the quantification of public exposure, actual and potential, such as information on local demographics, sensitive areas (i.e., schools and preschools, healthcare facilities, retirement communities), and information regarding specific cultural factors that may increase risk for subpopulations (i.e., tendency to eat more than average levels of fish, subsistence hunting).

Last, information and data are needed for identification and characterization of community issues and perceptions of site-specific hazards and associated risks.

This last component lends itself to a vast array of possible inputs, including meetings with community groups, public opinion surveys, and screening of local news articles. It is also critical to gather information on risk-benefit tradeoffs at specific sites (such as quality jobs or increased tax base), which may mask the real risk associated with the site.

This kind of community-based hazard and site ranking system lends itself to a variety of applications, both as a management tool and as a public relations and educational tool, whether or not it is used in the context of siting a medical research facility.

## Management

For communities where there may be multiple discrete sources of environmental contamination, such as industrial point sources and/or abandoned landfills, a community-based risk modeling system can be applied to

identify specific sites that, if rededicated, would result in maximum risk reduction in both absolute terms and in terms of public perception. In addition, this approach would help to prevent the expenditure of funds to clean up one site where another nearby source would maintain the risk to public health and the environment.

## Public Relations and Education

Involving community stakeholders is an essential part of the community-based hazard and site ranking concept. Community members who are active participants in the assessment process can become invested in the rededication. As a result, they often become knowledgeable advocates who collaborate with engineers and regulators to achieve speedy rededication, to the overall benefit of their community, rather than emotional advocates who delay or prevent the project.

## Partnership with Local Government

How are biomedical research facilities perceived in the community? Perception is a real issue, especially for people on the outside looking in. It is natural for them to wonder, "What is going on in there?" In the absence of any other information, it is also natural for them to wonder, "Is there anything in there that can hurt me?" It is this lack of information that leads to misconceptions, rumors, and fear that every government agency is a sinister conspiracy with something to hide.

The antidote to misconception is more information and more openness. A proactive outreach and community awareness program is the key to establishing a good relationship with the neighbors. These efforts are analogous to a safety program that focuses on preventing accidents rather than on repairing damage, or a risk management program that assesses the possibility of harm and acts to prevent it. Similarly, public awareness programs should focus on correcting and preventing misconceptions.

It is important for a biomedical research facility to reach out to its neighbors and to develop cooperative and effective partnerships with them. Federal agencies, in particular, are often criticized because they do not understand or pay attention to the complexities and dynamics of the population surrounding them. The public now demands and deserves to be heard in matters involving their communities. In this social climate, government facilities are obliged to learn more about their neighbors and discover new ways of interacting with them.

As simple as it sounds, the best way to ascertain what the public thinks is to talk to them. It is important to be very clear about

the level of interaction expected with the community. A good goal would be to meet with each of the surrounding homeowners' associations at least once a year. Once these associations become partners, they can "buy into" the program to assure that they remain part of the process.

An important benefit of talking to neighbors is that an agency can anticipate their concerns and try to accommodate them. This accommodation will help foster goodwill rather than resentment. It also provides a way to open doors before there is an angry mob trying to beat them down. Another way to open the doors is to solicit the press as a potential partner. Inviting local reporters to visit the facility and allowing them to write candidly about its operations and management will provide an excellent conduit for the flow of information to the community.

In the case of NIH, the community's concerns involved clean air and other environmental concerns, as well as biological and chemical agents. NIH responded to those concerns through public outreach and public involvement and changed its operations as well. The result was that the NIH community has become a partner in developing and implementing new technologies such as natural gas power generation.

This partnership with the community also allowed NIH to commission an independent review of the incinerator issue to determine if its operating procedures had created any risks to the community. In similar situations, an outside consultant with no stake in the outcome may be able to win over the local population more readily than a government expert. When selecting this consultant, however, the agency should be sure that he or she makes final judgments on the basis of science and that his or her credentials are genuine.

Partnerships with state and local governments also help Federal facilities strengthen their relationship with the community. For example, state agencies can call public information meetings to solicit public comment about hazardous waste permits and air emission sources. Even when there is no requirement for such a forum, voluntary outreach efforts such as a town meeting can do a great deal to shed a favorable light on an agency.

However, it is absolutely necessary to prepare for the meeting by anticipating questions that may be asked and being ready to answer them with facts presented in a nonpatronizing manner. Leave out acronyms and jargon; they can alienate an audience. Do not fall back on secrecy—the veil of secrecy is a sure road to failure when it comes to community relations. If there is a reason for confidentiality, try to explain that reason in a way that does not compromise security, but remember that it is precisely the excessive secrecy at

Roswell, New Mexico, that convinces some people there must be aliens there.

If they want these community outreach programs to demonstrate commitment, government agencies must provide the resources needed to make the community program viable. A poorly planned effort, or one that stops after a year or two, will do little to reassure the community that a facility is a good neighbor.

Finally, any biomedical research facility must accept the challenge of meeting with the people of the community and giving them the information they need. It is unquestionably hard and sometimes contentious work, but the resulting partnership will benefit everyone involved. Not everyone will be pleased all of the time, both at the agency level and among community groups, but efforts to foster good relations with the community can have lasting benefit to all concerned parties.

### **Advantageous Liaison: Research and the Community**

Over the past 20 years, the American public has become increasingly concerned about the siting, construction, maintenance, and operation of research facilities that might add physical, chemical, and biological contaminants to a community's air, water, and land resources. Some of these concerns are fueled by the fact that environmental risks are not shared equally and that some neighborhoods suffer a disproportionate share of the resulting disease, dysfunction, and premature death. Sharply etched into the archives of community health and regularly recited in public forums and college classrooms, is the Love Canal "bad neighbor" episode. Between 1942 and 1952 Hooker Chemicals and Plastics used Love Canal in New York State as a dump for more than 21,000 tons of mixed chemical waste. Twenty-five years later the area was declared an environmental emergency, and 950 families were evacuated from their contaminated properties. Many of America's urban centers are scarred by contaminated and/or abandoned industrial sites—a legacy resulting from improper and inadequate management of hazardous substances.

Contaminated Federal facilities, including both nuclear weapons sites and nonnuclear industrial sites, provide equally vivid examples of ineffective management of toxic and hazardous materials that have placed communities at high risk of environmental harm. These conditions have generated acrimonious debate among research proponents, community members, environmental activists, and Federal program managers. A recent addition to the debate is Paducah, Kentucky, where a government-owned uranium plant has reportedly dumped radioactive waste outside

the facility's fences in areas readily accessible to the public.

Other social developments have helped put biomedical research facilities on the front page of community newsletters and at the top of the agenda of rebellious neighborhood meetings. The fusion of university research and industrial development, while generating jobs and contributing to state and local coffers, has also given rise to concerns about who bears the risks of a technology and who gains the benefit. In some cases, those who bear the immediate risks are not the same people who gain the benefits, and this unequal distribution leads to conflict. This kind of conflict is clearly evident in debates about the siting and operation of research facilities that might increase automobile traffic or release toxic agents into the environment. Even in agricultural research, there are questions about the safety of genetically modified crops. Buoyed by the media storm in Europe, groups in the United States have stepped up their assault on all forms of biotechnology.

In recent years, clusters of acute and chronic diseases, real or imagined, have led to antagonism and mistrust in neighborhoods near research and industrial parks. This attitude is further exacerbated when former workers allege that they experienced adverse health effects from in-plant exposures to hazardous substances. The tensions between community and research facilities increase significantly when the installation is surrounded by high electrical fences and guarded gates, suggesting that "something bad" is going on in there that threatens the health and well-being of the community. The media, specifically the popular press, have often inflamed community members rather than informing the debates about the risk and benefits of biomedical research.

As a result of all these factors, no environmental or public health argument is as complex and challenging, yet so central and urgent, as the development and maintenance of an advantageous liaison between a research facility and the community that surrounds it. This relationship is the indispensable foundation for enhancing community understanding and acceptance of biomedical research and its many ramifications.

Other names for this relationship might include "stakeholder participation," "community engagement," "community involvement," "community collaboration," "constituency building," and "community outreach." However, "advantageous liaison" captures the sense of cooperation between research facility and community members, for mutual benefit. Each community is different in demographics, socioeconomic status, and behavior, and the level of community participation on a given issue will be determined by the nature of the

issue, individual values, differential knowledge, and vested interest, to name only four variables. There are many different facets, and even factions, that will determine who in the community will be actively involved in research facility–community interactions and the degree of that participation.

However, although every community is different, and the specific political and organizational constraints can be daunting, a few general principles for developing advantageous liaison emerge from our work with NIH and its neighbors in Bethesda, Maryland, and from other such mediation assignments.

First, the research organization must recognize itself as part of the community and therefore work to develop a knowledge of its neighbors, their social organization, and the conditions and events of their everyday life. It is also useful to distinguish between passive community members (who are largely unaware of research–environment issues), attentive community members (who are aware of the issues and their ramifications), and active community members (who seek to make their views known and affect decisions of community relevance). These three groups have different attitudes and information needs, and they should be addressed accordingly. Such an approach can enhance the credibility of the research organization, and credibility is vital—without it, communication can lead to distrust and acrimony.

The second principle is the accessibility of researchers and managers to community members. The quality of access (i.e., how facility managers treat community members and their request for information relevant to the neighborhood) is important because community members value having someone inside the research complex who "really cares." Community members also value continuity. They appreciate being able to deal with the same individuals they have come to trust over an extended period of time. The Office of Community Liaison at NIH is an example of the type of administrative structure that can maximize accessibility and continuity. Its ongoing community task forces and advisory panels have also been effective in building relationships between the research staff and the community.

Third, the most productive interactions are those in which the research organization treats community members as full and legitimate partners in a two-way exchange. The landscape of government–community collaboration is littered with efforts that failed because government "experts" talked down to community members or gave the impression that they were meeting with their neighbors simply to mollify their "uninformed" lay perceptions. Advantageous liaison must

involve a dialogue, and it must also provide real opportunities for community members to have a meaningful voice in decisions made by the research facility that might adversely impact the community.

In this context, wise research officials will leave themselves ample room to adapt as their interactions with the community mature. When they review designs for a new facility, for example, community participants may be less interested in the science that can be done there than in potential exposures to liquid or gaseous residues. They may call for data on the performance of new or existing pollution control equipment or ask to have those systems evaluated by experts outside the research organization. They may also have different ideas about just how much information the public needs, and different strategies for dissemination and target audiences.

Finally, the best form of interaction is one that begins before there is a problem. Community members should be brought into the facility for regular discussions and tours designed to nurture their understanding of the research that takes place in that facility. Regular research updates, in the form of newsletters and briefings, can reinforce the belief of community members that the research institution is responsive to their input. In other words, the research facility gains allies rather than critics. This principle was given intellectual reinforcement at the World Conference on Science, which assembled last June in Budapest. Strong consensus emerged on the need for greater interaction among all stakeholders, improved communication of science to the public, and higher levels of scientific literacy so that people can understand and influence how science affects their lives.

It is a cliché that research informs and perpetually reinvigorates both professional instruction and service to humanity. It is a cliché precisely because it is true. Equally true, though less often remarked, is that research must be interactive and inclusive. Thus, advantageous liaison between biomedical research facilities and their neighbors in the community is crucial for maintaining a vigorous research enterprise and sustaining our international prominence in health research.

## Ongoing Community Involvement

An early conflict at NIH dealt with incineration of medical pathological wastes (MPW) for many years. In late 1993, a few local environmental activists petitioned the Nuclear Regulatory Commission to suspend the NIH license to incinerate radioactive MPW. Incinerators 1 and 2, which began operation in 1977 and 1982, respectively,

were shut down in December 1993 for reasons unrelated to the petition. Incinerator 3 continued to operate.

In May 1994 the local activists met with the NIH director to request that all MPW incineration on campus be stopped, and that a joint committee of NIH employees and community members be established to examine alternatives. The director agreed to stop incinerating waste on campus—a decision that may have been driven by the projected costs of upgrading the incinerator to meet anticipated tightening of emission limits—and he also agreed to a program of soil testing and analysis to address the community's concerns about the potential for adverse health effects resulting from past incinerator emissions.

The new director of the Office of Community Liaison met with the activist community members, who insisted that the director retain a consultant, recommended by them, to develop a soil-testing protocol and sampling plan. The director agreed to this demand but also involved the broader community by asking the Environmental Concerns Working Group to convene an independent panel of experts to review the test results.

The implementation of this process provided a number of lessons for both NIH and the involved members of the community, most of whom were new to this type of confrontation. Rather than reviewing the details of this case, however, observations and lessons may be extracted that may be of more general applicability and indicate how these lessons have been successfully applied at NIH in other cases.

**Lesson one:** Involve individuals who represent the broader community, not just the activist element, as well as local regulatory agencies and the relevant management elements on your own campus. In the case of NIH, the Environmental Concerns Working Group helped to develop plans for a community forum that provided an opportunity for neighbors to raise their concerns or questions about NIH operations and get immediate answers from NIH officials. A subcommittee of the working group reviewed the proposed soil-testing protocol and made substantial changes in its scope to ensure that it would produce the data needed to answer the community's questions. A community-only subset, this subcommittee also set the criteria for the Expert Panel, assembled a list of candidates, narrowed that list from more than 100 to about 15, and prepared the charge to the panel. Finally, they helped organize a second community forum at which the results of the soil testing were announced and explained.

**Lesson two:** Ensure that the public has easy access to environmental compliance information, as well as a way to make its

concerns heard during the design and implementation phases of programs with possible environmental effects. NIH accomplished this by establishing an environmental reading room on campus that contains copies of permits, environmental assessments, emergency response plans, hazardous waste reports, and community right-to-know documents. The director of the Office of Community Liaison also meets regularly with a community liaison council, provides regular briefings for neighborhood associations, publishes a monthly newsletter, and maintains a website for public access to information.

**Lesson three:** Screen all consultants and contractors who are to be employed in investigatory programs, even if they are nominated by the community. For example, the soil-testing plan submitted by the consultant who was recommended by the activists and retained by NIH would not have produced the information needed to resolve the issue. However, because an earlier question about the consultant's credentials had stirred the anger of the activists, NIH decided not to challenge the entire proposal, in the interest of moving the program forward. Instead, the Environmental Concerns Working Group proposed (and NIH accepted) changes that yielded better information on the concentrations and likely origins of contaminants in the soil.

**Lesson four:** Maintain close contact and dialogue with local media representatives. During the soil-testing process, it became clear to other community members that the activists were not interested in attending meetings or helping to find solutions; their preferred mode of participation was to complain via letters to NIH, local media, and political representatives. Other community members wrote their own letters to the local media, correcting the inaccuracies in news articles or activists' letters, and detailing the cooperative activities and decisions of the working groups.

The application of these lessons at NIH has resulted in substantially improved relations between the campus and the surrounding neighborhoods. Notable examples include *a*) the community's role in developing a master plan for future growth on the NIH campus; *b*) community review and acceptance of a proposed level 4 containment laboratory for research on multiple-drug-resistant tuberculosis; *c*) and review and acceptance of major on-campus construction activities that temporarily impede neighbor access to campus facilities. Local media coverage has become neutral, if not positive, and the community and NIH have become more understanding of each other's needs and goals. So far, at least, this has been a win-win relationship.

## Conclusions: Making the Model Work

For this model to be implemented, it is imperative that there be an institutional commitment to community relations from top to bottom. Commitment at the top brings not only leadership but also budget. A commitment to community interaction and partnership is not inexpensive and should not be a low-budget item. An agency will need to invest in staff and outreach activities as well as make changes in its operations. A commitment to change at the planning level, the engineering level, and the construction and buildings level also is required.

Institutionalize the process. Community relations cannot be something that merely responds to one crisis after another. The issues that will raise concerns in the community must be anticipated before they become controversies or media events. By establishing a central liaison office and creating community working groups to address specific issues, an agency can demonstrate to its community that it has a place to voice concerns and get answers to questions, and that they are partners in the ongoing effort to deal with those concerns.

For the partnership to work, there must be open communication, even a kind of transparency, between the facility and its neighbors. This is not about public relations. Indeed, it is as much about listening and asking questions as it is about talking. Moreover, it is not enough for the community relations office to speak to the community about the facility. It must also speak to the agency about the community in a way that clarifies and validates the community's concerns,

makes the facility responsive to those concerns, and ultimately leads to change.

To get a message across, the community relations office needs to go public. It can become visible through newsletters to every household, meetings with every civic association, and community forums when an issue of importance needs to be addressed. It can set up outreach programs, sharing resources with community groups and allowing neighbors to use and visit its facility. It can also allow neighbors to see regulatory reports and environmental impact statements, rather than using the Freedom of Information Act to delay the process.

Keep in mind that the community is not a single, homogeneous entity. Different subsets of the community will have different interests, concerns, and expertise, as well as different cultures and even different languages. As a result, it is important to broaden communications and outreach efforts to reach as many different groups as possible rather than staying locked in conversation with the groups that are most visible or most outspoken.

Do not try to impose a Federal model on a community. Put aside the Federal committee structure and adapt to a community-based approach or create a new model tailored for the task at hand. Bureaucratic language such as acronyms and technical jargon can alienate or overwhelm many members of the community. Find a style and a language with which they are comfortable. Talking with them, rather than at them, helps explain biomedical research and demystifies things that might provoke fear and uncertainty, such as genetic engineering or stem cell research.

Follow through on commitments. Integrity and honesty are as important in an institution as they are for the individuals who

work there, and they are vital in dealing with the community. Sometimes this is as simple as starting meetings on time or responding promptly and thoroughly to every letter and phone call from the community. But these seemingly simple things give neighbors confidence that their questions and concerns will be addressed. This is the necessary foundation for trust and credibility.

Finally, view yourself as part of the community and act accordingly. The community includes not only individual homeowners and civic associations but also the planning and regulatory agencies of cities, counties, and states. Your agency can influence both negative and positive outcomes for traffic and environmental management, and there may well be valid concerns about the environmental impact of your programs, growth, and operations. It is not enough to tell neighbors that biomedical research is nationally and internationally important. You must demonstrate to them that you are taking measures, in cooperation with county and state objectives, to address waste management, pollution abatement, and traffic reduction. By acting like a good neighbor, by stressing openness, responsiveness, and integrity, the biomedical research facility can engender credibility and trust in its community. This in turn allows the community to accept and support programs of biomedical research and the facilities that the agency must build and maintain to pursue its mission of promoting public health.

## REFERENCES AND NOTES

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